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‘I’m not insane, my mother had me tested’: The risk and benefits of being labelled ‘at-risk’ for psychosis

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Abbreviated Title: Being labelled ‘at-risk’ for psychosis.

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Abstract

In this article we examine the identification of young people deemed to be at an elevated risk of developing psychosis (often referred to as an At-Risk Mental State for psychosis).

Although this is not a new concept within psychiatry, there has been a growing interest in this topic because of the proposed inclusion of an official 'Psychosis Risk Syndrome' in the 2013 Diagnostic and Statistical Manual. Although we discuss the risks and benefits associated with the categorisation of individuals based on the concept of risk itself, we also draw upon observations from one of our own research study. We interviewed six adolescents with an identified At-Risk Mental State analysing the data using an Interpretative Phenomenological Analysis framework. We identified three key themes: *'It is better to say it', 'How others would take me' and 'Just to have somebody to talk to'*. Within these themes participants endorsed risk identification as a means of personally justifying and explaining their current symptoms, as well as providing a sense of optimism that their condition was not yet fully formed. Concerns regarding stigmatisation were identified although rarely experienced. These findings indicate that there are indeed personal benefits for screening for psychosis risk in young people, despite the 'undesirability' of identification reported in other areas of health. The benefits observed may reflect genuine differences in adolescent mental health or the methodological constraints of this exploratory study. Nevertheless, the results contribute to the understanding and on-going debate of screening for illness in potential 'at-risk' populations.

Keywords: categorisation, risk, psychosis, mental health, young people

Introduction

In this article we examine the identification and treatment of young people deemed to be at an elevated risk of developing psychosis (often referred to as an At-Risk Mental State for psychosis). The purpose of this article is to consider the various risks and benefits of diagnosis and screening in general but more specifically within the context of psychosis risk itself. We devote a significant proportion of this article to the examination of one of our own research studies in which we interviewed a small number of adolescents with an At-Risk Mental State about their personal experiences of identification and treatment. This study will set the scene for a final discussion into the future of psychosis risk categorisation and possible implications.

Predicting and categorising psychosis

Being at-risk of psychosis

Psychosis is a psychiatric term used to describe a state characterised by disturbances in sensory perceptions, content of thinking and ideation. Symptoms of psychosis include the presence of clear hallucinations and delusions, thought disorder and catatonia (McGorry *et al.*, 1996). These symptoms, often referred to as ‘positive’ symptoms, may co-occur or in some instances co-exist with ‘negative’ symptoms such as reduced motivation, social withdrawal, poverty of speech and affective blunting.

Although research findings vary according to the population studied and length of follow-up, often the outcomes of those affected by the condition are poor, both in terms of illness course and day-to-day functioning (Leff *et al.*, 1992, Mason *et al.*, 1995). The illness process may have significant detrimental effects on personal, social and occupational functioning (Agerbo *et al.*, 2004, Marwaha and Johnson, 2004) whilst outcomes may be

especially poor for those who develop psychosis as adolescents (Mason *et al.*, 1995, Schmidt *et al.*, 1995, Fleischhaker *et al.*, 2005). Patients with the condition also experience a higher than expected mortality rate with suicide accounting for a large proportion of deaths (Harris and Barraclough, 1998). Psychotic illness generates both direct (health care related) costs as well as indirect costs to society through unemployment and financial benefit provision. Indeed a significant proportion of health care expenditure (in terms of in-patient care and medication) is consumed annually in relation to psychosis care (McCrone *et al.*, 2008; NICE, 2008).

Given these individual and societal costs it is no surprise that for almost a century there has been interest in the possibility of intervening early, before the onset of a full psychotic illness (Sullivan, 1927/1994). Within the last twenty years, criteria to identify individuals deemed to be at imminent risk of developing the condition have been established with the ultimate aim of preventing a future psychotic episode altogether. By focussing on the developmental period of peak onset and combining a variety of different risk factors such as genetic predisposition and clinical features observed during the earliest stages of the illness, individuals can now be labelled as having an 'At-Risk Mental State' for psychosis with the subsequently developed criteria referred to as Ultra High Risk (Yung *et al.*, 2003).

This At-Risk Mental State indicates a high probability but not a certainty of developing a psychotic disorder in the near future (McGorry and Singh, 1995) and is predominately characterised by attenuated or sub-threshold positive symptoms associated with help seeking behaviour and chronically low or deteriorating psycho-social functioning. As hoped, the adoption of this Ultra High Risk based strategy initially led to a significant increase in the predictive ability to identify individuals destined to become psychotic. In Australia for example where the criteria was first conceptualised, transition rates (to psychosis) of around 40-50 per cent within a 1-2 year follow up period where subsequently

observed (Yung *et al.*, 2003, Mason *et al.*, 2004). Since then the At-Risk Mental State label has been widely applied in research and clinical settings worldwide.

In recent years, interest in this ability to predict psychosis, through risk identification, has grown to the extent that a 'psychosis risk syndrome' was proposed (although later withdrawn) for possible inclusion in the latest version of the American Psychiatric Associations Diagnostic and Statistical Manual of Mental Disorders (DSM-V; Carpenter and Tandon, 2013).

Risks and benefits of diagnosis

The benefits of being diagnosed with a recognised illness have long been recognised, beginning with Parsons' (1951) identification of the sick role, giving permission to be excused from normal commitments in return for compliance with the expectation of a desire to get well. The sick individual is treated for their illness rather than blamed for their deviance (Freidson, 1972) and diagnosis acts as a means to explain and allow for what makes the individual 'different (deviant) from the norm' (Jutel, 2009, p. 279). However, being labelled as having a disease, particularly a chronic illness, may result in 'biographical disruption' (Bury, 1982), 'loss of self' (Charmaz, 1983) and require 'narrative reconstruction' (Williams, 1984) which has an impact on the labelled individual's identity affecting how they make sense of themselves and their life. As Jutel and Nettleton suggest:

A diagnosis can vindicate and blame, can legitimise or stigmatise, can facilitate access to resources just as it can restrict opportunities. A diagnosis can be welcomed or eschewed. (Jutel and Nettleton, 2011, p. 797)

One of the particular issues with diagnoses in mental health relates to the problems of classifying diseases; until something is classified as a disease, it cannot be diagnosed, but as the example of homosexuality shows, being listed as a disease in the Diagnostic and Statistical Manual and later removed, diagnostic categories are not certain and fixed. The Diagnostic Statistical Manual of Mental Disorders was first produced by the American Psychiatric Association in 1952 (DSM-I), and is now in its fifth iteration (DSM-V). It is heavily relied upon by clinicians, researchers, insurance companies and policy makers in order to classify psychiatric symptoms into diagnostic categories, thus potentially aiding understanding and facilitating treatment of a particular disorder. It has been controversial, particularly concerning the inclusion and exclusion of some conditions, for example, homosexuality as mentioned above; earlier versions have been criticised for ‘psychiatric expansionism’ (Holmes and Warelw 1999; p172) by labelling almost all behavioural traits as potentially indicative of psychiatric disorder. Mental health conditions in particular are difficult to diagnose accurately especially in terms of whether they will lead to violent behaviour (Langan, 2010), and distinctions (between schizophrenia and personality disorder) are not clear cut, with diagnosis sometimes being made on pragmatic grounds (Warner and Gabe, 2004). Manning (2000) argues that the classification of personality disorders is a particularly difficult, if not disputed area in terms of diagnostic categories and the Diagnostic and Statistical Manual.

Classifications and diagnosis are particularly important in mental health because of the link with risk assessment. Psychiatrists rely on ‘endlessly shifting mental disorder classifications’ (Heyman *et al.*, 2012, p.109) as they attempt to identify and assess risk in order that it can be managed. As McGuire points out, risk assessment is legitimate in that it attempts to identify people who might harm others (as well as people who may harm themselves) and:

The overarching aim is the avoidance or minimisation of harm. However, unless risk assessment is completely veridical, axiomatically there exists the possibility of error such that other harms can be done. (McGuire, 2004, p. 329)

Those other harms include stigmatisation and negative aspects of being labelled, which for adolescents may be particularly challenging. Some diagnoses in children and young people, such as Asperger's Syndrome for example, may influence a child's life to their advantage or disadvantage but have clear long term risks should diagnosis not take place (Portway and Johnson, 2005). As we will now examine, these same disadvantages and advantages may accrue to adolescents diagnosed as 'at risk' of psychosis.

The risks of being labelled 'at-risk'

Research in areas such as genetic testing indicates that people are not always keen to know their own risk status especially if, as in the case of Huntington's disease, they can do nothing to change the trajectory of the disease (Wexler, 1995). When individuals do learn their risk status, it can often have a powerful impact with patients and family members experiencing acute anxiety, depression and interpersonal strain (Heinssen *et al.*, 2001). Many individuals then go on to report examples of discrimination and hostility from life insurers, employers, family members and health care professionals (Yang *et al.*, 2010). In the field of testing for breast cancer risk in America women often opt to pay for testing privately to avoid raising the suspicions of current and future insurers (Corcoran *et al.*, 2005).

With Huntington's disease the probability of developing the condition after positive identification is virtually 100 per cent (Corcoran *et al.*, 2005). Using the Ultra High Risk criteria to identify an At-Risk Mental State for psychosis does not carry the same predictive certainty. As we noted above initial research indicates a 40-50 per cent transition to psychosis

within a 1-2 year follow up period (Yung *et al.*, 2003, Mason *et al.*, 2004); these figures have gradually declined as more and more individuals are recruited to research studies. More recent figures indicate a transition rate of around 16 per cent after two years (Yung *et al.*, 2008). This poor predictive ability is certainly a problem when we consider that various interventions have so far been used in order to alter the proposed trajectory of those deemed 'at-risk'. For example antipsychotics and antidepressants have been adopted based upon the notion that brain maturation is disturbed in those with emerging psychosis (Pantelis *et al.*, 2003). It has been proposed that these agents could potentially protect or limit the potential decline in brain maturation (Berger *et al.*, 2007) and significantly alter and improve the long term prognosis of an individual's condition by potentially limiting its progression and preserving a person's ability to respond to future treatments (Perkins *et al.*, 2005).

However, little is known about the effect that antipsychotic medication may have on the developing adolescent brain (Bentall and Morrison, 2002) and without infallible prediction many of those treated this way will have been exposed to risk of taking antipsychotic medication unnecessarily. Studies have suggested that young people in particular are prone to neuroleptic side effects (Fraguas *et al.*, 2008) whilst long term use carries the possible risk of brain shrinkage (Ziermans *et al.*, 2011). Indeed significant side effects have been noted in several At-Risk Mental State trials thus far, such as weight gain (McGlashan *et al.*, 2006, Woods *et al.*, 2007), and increased prolactin levels resulting in high study drop out (Ruhrmann *et al.*, 2007). Although it is relatively easy to highlight the side-effects and potential negatives of medication use, limited attention has been directed towards the use of psychological therapies that have also been utilised as a form of psychosis prevention. Indeed side effects are likely to exist but they appear much harder to quantify given the lack of formal testing. For example the offering of Cognitive Behavioural Therapy

to individuals who may never develop psychosis and currently have no diagnosable mental health problem, could be pathologising.

From the current criteria and research conducted so far there is also no consensus as to how long identified individuals should be treated. It is also unclear whether an individual remains 'at-risk' for the rest of their lives even if the factors believed to be predisposing them to any future risk have remitted/been removed. Some research groups have withdrawn the label of risk when individuals fail to reach the Ultra High Risk criteria upon reassessment twelve months after initial identification (Simon and Umbricht, 2010).

There is a strong possibility that individuals thus labelled will experience alienation, since obtaining a diagnosis of psychosis is often perceived as detrimental with many individuals feeling as if others perceive them to be different or unacceptable (Knight *et al.*, 2003). Opponents of the psychosis risk syndrome suggest that any use of a 'psychosis' label would interfere with a patient's ability to communicate with others, making them withdraw or limit social contact to those accepting of their condition. Adolescents may be particularly vulnerable to labels which stigmatise, because they are at a stage of life when social acceptance and autonomy are key to their identity formation (Moses, 2009). For adolescents, anticipated peer rejection is probably a major concern given that many people endorse the view that children who obtain mental health treatment are likely to be outsiders at school. Adolescents' perceptions of peers with psychosis are also extremely negative with the majority endorsing attitudes that suggest those with the condition are more violent, suicidal and academically poor. Adolescence is a time when young people are rapidly negotiating developmental goals and obtaining their own self-concept. Consequently a mental illness label may interfere with these processes. There is also a risk that the illness role becomes central to the young person's identity and threatens a future sense of normality. This is something that has been observed for other conditions with about 20 per cent of adolescents

identifying their own mental illness label as a core aspect of themselves (Moses, 2009).

Labelling seems to have a greater impact (in terms of self-stigma and secrecy) among adolescents who are younger with less well formed identities. It has also been shown that labelling-induced stigma can be devastating in terms of reduced self-esteem, greater feelings of depression and demoralisation, poor treatment adherence and reduced social contact making a relapse more likely (Yang *et al*, 2010).

Parents of those with 22q11 deletion syndrome (a genetic syndrome resulting from the deletion of a section on chromosome 22) report the strain of living with uncertainty (these individuals have a 25-30 per cent risk of developing psychosis sometime during their lives) and the struggle to differentiate between normal changes in behaviour and those that are cause for alarm ('over vigilance'; Hercher and Bruenner, 2008). Although individuals with 22q11 are often at risk for other medical conditions, families indicate that the risk of psychosis causes them the greatest anxiety. Qualitative research exploring the experiences of siblings of individuals with psychosis indicate that brothers or sisters also act as a valuable resource in engaging in recovery, normalisation activities and providing opportunities for socialising (Sin *et al.*, 2008). However, in this context of risk identification it is unclear if siblings would come to perceive themselves as being at risk based on their brother or sisters supposed status.

Potential benefits of identifying those 'at-risk'

As we have previously stated the ultimate aim of identifying risk in this instance has been to prevent the onset of a full first episode of psychosis. If these aims are indeed successful, this would have significant implications for identified individuals in terms of quality of life and future access to education and employment. Financially the benefits of potentially preventing psychosis, in even a handful of individuals (by reducing future long term medication costs,

inpatient bed days, welfare benefits) are likely to exceed the cost of identifying and treating those at supposed risk. However, even if professionals cannot prevent transition, prompt and effective treatment as soon as the individual becomes psychotic may preserve functioning and improve short to long term outcomes (Yang *et al.*, 2010). If identification is not made (especially in adolescents where long term outcomes associated with psychosis are worse; Schmidt *et al.*, 1995, Fleischhaker *et al.*, 2005) this could represent a significant missed opportunity.

Advocates of any formalised psychosis risk syndrome have argued that clearly defining the condition will direct future research and resources to an important clinical population as well reduce the potential for misdiagnosis. Psychiatry will be more aligned with other fields of medicine that identify risk factors for the purposes of instituting preventative interventions (Nelson and Yung, 2011). For example, graduations of blood pressure and cholesterol have long been identified as conferring quantified risk for cardiovascular disease. Here preventive efforts have been applied to promote and/or preserve good health (Corcoran *et al.*, 2010).

Although it has been postulated that those who never make the transition to psychosis may experience a lasting sense of fragility, others have suggested that individuals with an At-Risk Mental State are by no means asymptomatic (Ruhrmann *et al.*, 2010). Engagement and support from services (due to identification) may help to shed light on the various presenting symptoms (distressing psychotic like symptoms, depression, anxiety and other common co-morbidities that are often present in this patient group; McGlashan, 2005). The label may result in prompt and effective treatment reducing symptoms thereby decreasing stigma (Yang *et al.*, 2010) as symptoms and behaviour usually shape community rejection rather than labels themselves.

Some researchers have suggested that the At-Risk Mental State label, rather than increasing apprehension as is the case with a diagnosis of psychotic illness, may open the door for new optimism that outweighs any anxiety as symptomatic patients know that some form of treatment is forthcoming (Corcoran *et al.*, 2005). By not providing a label for a person's symptoms and an adequate explanation, individuals may tend to stay in a state of denial (thus letting their condition worsen) or they may never experience the sense of relief a diagnosis/label can provide. Feelings of confusion and worthlessness are often replaced with relief when service users affected by psychosis are provided with accurate meaningful information (Kilkku *et al.*, 2003; Koivisto *et al.*, 2004). Coping, engagement, medication adherence and long term outcome also appear to be much improved when people are more informed about their diagnosis of psychosis (Dudley *et al.*, 2009). These observations are confirmed in adolescents diagnosed with depression (Wisdom and Green, 2004) since many appear to experience relief when hearing about their diagnosis as it validates their distress and reassures them that they were not the only person to experience these symptoms. It was also observed in this study that the label helped young people make sense of their distress and seek information to reduce their symptoms. Not only may the identified individual benefit from identification but family members may do so as well. Parents of individuals with psychosis suggest the label of a mental illness can offer a way to deal with the negative feelings they had experienced towards their child and a diagnosis gave them hope of potential treatment and recovery (Muhlbauer, 2002). Accurate psychiatric labels may also help young people in that they are more likely to be perceived as 'sick' (and therefore deserving of help and sympathy) rather than 'weak', although accurate labelling of psychosis must address widely-held ideas about dangerousness and unpredictability (Wright *et al.*, 2011). At-risk labelling is potentially harmful but as we can see in many cases it may also be helpful and important from the perspective of the individual, supporting family and society as a whole.

What are the views of those individuals subsequently categorised?

Despite the numerous arguments for and against categorisation, many of the views expressed have not considered the potential concerns of those individual who have be so categorised.

As Yang et al noted that:

No studies to date have systematically examined how any potential stigma induced by the psychosis risk syndrome impacts identified patients (Yang *et al.*, 2010, p. 43)

Speculative observations from one or two specialist at-risk clinics have suggested that young people and their families experience a range of feelings and emotions when presented with the label. Some experience relief and tend to feel ‘better’, possibly because they are not currently psychotic (Yung *et al.*, 2007). Others demonstrate concern, scepticism and denial in response to the news (McGlashan *et al.*, 2007) which does not seem surprising given many young people’s tendency to ignore psychotic symptoms in order to cope with their difficulties (Boydell *et al.*, 2006).

In order to address these concerns our research group undertook the first and at the moment only qualitative study with the aim of investigation the understanding and experiences of adolescents thus categorised (Welsh and Tiffin, 2012; Welsh, 2013). The decision to focus upon an adolescent age group was based on the notion that wrongful identification and potentially harmful and unnecessary treatment would have the greatest impact in those so young.

Methods

Our aim was to conduct an exploratory study using a small pragmatic survey in order to capture participant experience. We chose a semi-structured face-to-face interview design to obtain deep personal discussions, allowing for researcher flexibility in questioning style and content. We decided to undertake individual interviews conducted by a mental health professional rather than focus groups or use an independent researcher for ethical and practical reasons. These included the possible discussion of highly sensitive and personal information with young, vulnerable and symptomatic participants with difficulties associated with social anxiety, suspiciousness and trust.

We recruited six adolescents (aged between 13-18 years of age), accessing mental health services in the North-East of England for the study on which this article is based. These individuals were selected opportunistically from a cohort of adolescents already participating in another local study, conducted by the primary author (Patrick Welsh), aimed at characterising how adolescents with an At-Risk Mental State initially present to mental health services in terms of symptomatology and psychosocial functioning (Welsh and Tiffin, 2013). We only invited individuals to participate if they had been identified with an At-Risk Mental State for a period of at least six months and had not developed a full blown psychotic illness within that time. Conducted interviews were recorded and fully transcribed with the written informed consent of the participants. The study was given ethical approval by the Durham University School of Medicine and Health Ethics Committee and the National Health Service Research Ethics Service. The demographic details of each participant and assigned pseudonyms (in order to protect identity) can be seen in Table 1 and indicate a relatively heterogeneous group in terms of age, gender and mental health status at the time of interview.

[Insert Table 1 here]

As the study was concerned with obtaining rich detailed accounts of peoples experiences of being labelled (as well as experiences of treatment and support), we analysed all data using an Interpretative Phenomenological Analysis (IPA) framework (Smith *et al.*, 2009). Interpretative Phenomenological Analysis is a relatively new technique that focuses in detail upon how individuals experience and perceive major life events and is informed by three key areas of philosophy: phenomenology (the study of experience and how we come to understand our lived world), hermeneutics (the theory of interpretation) and idiography (the study of the particular/individual). The technique aims to avoid making prior assumptions and hypotheses and sees the research participant as the expert who can offer understanding by relaying their own stories, feelings and experiences. After the initial descriptive analysis we undertook a more interrogative and interpretative examination of the transcript and initial notes. We aimed to move to a more conceptual level, moving away from the more explicit claims of the participant and incorporating elements of personal reflection, experience and questioning by the analyst. We sought to identify issues which were perceived to be important in understanding the participant's world and the matters they were discussing (conceptual comments). Once we had analysed each transcript we looked for patterns and connections across cases. This involved identifying themes which are the most frequent or potent. For example the frequency of comments relating to the 'Reactions of others'; family, peers or society as a whole and actual or predicted, were represented in all participant accounts (except Donna's) making this a significant component for the analysts in understanding the participants experience.

Findings

In our analysis of the interview transcript we identified three major themes and in this article we will focus on the two themes that relate to potential risk/benefits of labelling discussing each in turn.

'It is better to say it': information about risk status

In their interviews all participants said that they wanted to be informed about their condition/risk status. In reflecting upon his own personal contact with mental health services, Frederick (an 18 year old) stated that withholding information could just make things worse over the longer term and he found it refreshing for professionals to be upfront with him about his condition:

You were really straight forward and that's the way I prefer it. I don't like it when people tiptoe around things 'cos then, when you actually realise it [that you are ill] it just hits you hard and causes too much stress. It is better if you are going to be told something like you have schizophrenia or we believe that you are suffering from a form of depression, it is better to say it.

For another participant, Ethan (aged 15 who we asked specifically about his reaction to being identified as being 'at-risk'), the At-Risk Mental State label confirmed that other people have similar difficulties. This appeared to help him normalise his pre-psychotic experiences and self-perceptions.

It felt more of a relief to sort of know you weren't alone.... you feel a lot more sort of comfortable knowing that you are not a freak.

This sentiment was also echoed by Andy (a 16 year old) when asked to describe his own experiences of being told he was at-risk of developing psychosis. He reasoned that if the condition has been recognised and had a name then mental health services should be able to help him. Andy also said that he felt reassured by professional validation of his beliefs that something was wrong.

I knew there was obviously something wrong and the fact that somebody acknowledged that and I kind of had something to go away with that I knew somebody else had already noticed, then I could work with that... If I hadn't been given anything then I might have been more worried about the future and stuff because I didn't know what was going on. With, the At-Risk Mental State kind of label it was helpful 'cos then I could read up and I knew how it was going to be dealt with.

'How others would take me': The response of peers

Participants in our study were concerned about whether or not to communicate the label to other people and the effect of this information on *'how others would take me'* (Claire aged 16) if they knew. Both Bethany (aged 13) and Claire especially felt anxious about what people might say about them in the future if they discovered they had been given a psychiatric label. Claire noted that *'they [other people] are going to look at me and think what's wrong with her'*. For this reason remaining quiet was seen as the best option and utilised frequently when dealing with other peers, teachers and even family members with Bethany stating that: *'I don't go mentioning it to anybody.'*

Although participants were understandably reluctant and cautious about telling their friends about their condition, chance incidents could bring their condition out into the open. For Bethany the experience of having her thought diary read by one of her friends was

actually positive as her worst fear of being perceived as ‘crazy’ or a ‘psycho’ was not confirmed. In fact Bethany said that the incident showed that despite her condition people were still willing to accept her as a friend.

I kept a diary of my thoughts and feelings and things, like I was told to do and I took it to school in case I had an experience and as I was writing, one of like my closest friends, who she didn’t actually know about my problems, she snatched it off me ‘cos she thought it was just like a general book I was writing in and she had a look and she felt so sorry for me. So that made me a bit more happier that she didn’t exactly think I was completely crazy.

Although having his diagnosis made public did not appear to have been as significant for Frederick (aged 18) in terms of his self-esteem, it did serve to confirm that his friends were both supportive and generally concerned about his well-being. In his interview he described how and why he could no longer keep his condition private and the positive reactions of his friends:

Most of my friends saw me taking my medication and they asked, they realised that it wasn’t multivitamins or anything like that ‘cos they saw the actual pill packet and asked what I was doing and I thought well there is no point in hiding it and I told them. And they just asked how I got to the state I was in and if there was anything they could do to help.

Despite positive interactions with close friends, some individuals did experience some negative stigmatisation from their peers. Although Bethany (aged 13) had been particularly

worried about experiencing this type of reaction, the experience when it occurred did not appear to be particularly upsetting. Her friend's opinions and their unconditional acceptance appeared to be the only view that really mattered upon reflection on these incidents.

Yeah a few people have 'cos I have the odd few people who take the mick out of me but then I have my close friends that don't like, don't, haven't really changed much, when I have told them.

Discussion

Much of the literature on risk and screening points to the undesirability of being labelled as ill or at risk of disease as a result of screening. This is particularly the case where people have been symptom free, for example never having experienced ill-health related to their bones but having been diagnosed as at risk of osteoporosis (Salter *et al.*, 2011); although it may also be the case where individuals or their families have noticed changes, for example relating to the development of dementia (Milne, 2010). In addition, risk models are increasingly being used to identify high risk populations, particularly for certain cancers, who may then be offered screening (Holmberg and Parascandola, 2010). This then creates new categories of disease-free but 'at risk' individuals in need of intervention; furthermore, 'being given a risk status during a symptomless pre-disease state may change an individual's self-perception as healthy into that of a patient' (Salter *et al.*, 2011 p810); and this may change their behaviour (such as not wanting to go outside any more) or their feelings about themselves in negative ways.

The undesirability of a diagnosis resulting from screening seems to be strongly related to whether or not the person now labelled as a 'patient' had experienced any symptoms prior to being given the 'at risk' label. With physical diseases, the labelling may have taken place at a symptomless, or 'pre-symptomatic' stage, with mental illnesses the individual may

already be aware of themselves as being different (Portway and Johnson, 2005). As Portway and Johnson point out, labelling people as anything other than “normal” is unpopular, but there are positive as well as negative consequences of applying a diagnostic label. In particular, with some diagnoses, such as Asperger’s syndrome or an At-Risk Mental State, there are risks associated with not having an early enough diagnosis, such as not having access to treatment, educational interventions or social support that makes the problem manageable. For our participants, being screened and given a diagnosis provided benefits in the form of relief: being able to ‘put a name’ (Jutel 2011) to a problem they already felt they had; and also in the form of managing: now they had an accepted label, it could be managed.

Some screening, for example genetic and pre-natal screening, gives rise to ‘manufactured uncertainty’ (Giddens, 1994) and surveillance anxiety (Burton-Jeangros *et al.*, 2013), particularly in terms of waiting for an outcome that may or may not happen (the emergence of a hereditary condition, the birth of a chromosomally abnormal baby), and are examples of a risk approach which is designed to improve control over bad outcomes but at the same time increases uncertainty for the individuals concerned. In contrast, for our participants the screening process and subsequent diagnosis had increased their feelings of certainty, even though they were also potentially waiting for an outcome that may not happen, in the sense that although they were labelled as having an At-Risk Mental State, they may never develop psychosis themselves.

Being given a diagnosis or an ‘at risk’ label allocates the individual to a new social group (Milne, 2010), and where mental health is concerned this is often one that is viewed negatively. One of the reasons that older people resist a diagnosis of dementia is due to its association with several social problems (Milne, 2010) and the young people in our study were certainly aware of the potential drawbacks to their diagnosis becoming known, in terms

of how their friends and people around them would react. However, despite their fears, their friends had been understanding and supportive once their diagnosis had become known.

While many challenge risk surveillance and the expansion of screening, for the individuals in our study screening gave them more control and relieved, rather than exacerbated, the anxieties they had been feeling about their mental state.

Future directions

Since this study (at the time of writing) is novel in the examination of experiences relating to the assignment of an At-Risk Mental State label, it is difficult to assess the transferability of our findings given the lack of previous literature. However, the recruitment strategy adopted by the study may have been biased to those with positive experiences of services and labelling, given the opportunistic nature of selecting individuals already engaged within a research project and the decision not to interview those who had subsequently developed psychosis. In reflecting upon the usefulness of the Interpretative Phenomenological Analysis approach for the purposes of this study, the aim of obtaining rich and detailed accounts from individuals experiencing an At-Risk Mental State were only partly fulfilled. Although there was sufficient data to generate themes and inferences from the interviews conducted, many participants found it particularly difficult to fully articulate their experiences. At times, these difficulties led to relatively short and superficial interviews. More detailed and ‘open’ accounts in relation to personal experience, may have been forthcoming had we employed a service user researcher (rather than a psychiatric professional) to conduct subsequent interviews. Studies that have adopted this method have predominately obtained more critical and potentially ‘honest’ accounts of service provision (Simpson and House, 2002). All these factors make further exploration of what it feels/means to be labelled as having an At-Risk Mental State for psychosis even more compelling.

Indeed, the omission of the proposed psychosis risk syndrome from the Diagnostic and Statistical Manual of Mental Disorders, version five (DSM-V) may not signal the end of this on-going debate. For example it is highly likely that individuals presenting to mental health services will continue to receive an At-Risk Mental State label for the foreseeable future, given its (in some areas widespread) clinical use. A possibility has therefore been mooted in relation to a change in terminology and a move away from categorisation via risk status. The proposal for an 'Attenuated Psychotic Syndrome (APS)' is one suggestion which may be more palatable for many different stakeholders. In the first instance it solves the problem of declining transition rates and identification of 'false' positive cases (individuals who will never go on to develop psychosis) as all patients would already have distressing sub-threshold psychotic symptoms. Kaymaz and van Os, (2010) have questioned the accuracy of this notion of risk before, arguing that identified individuals should not be considered 'at-risk' but 'cases' in their own right because of their already elevated levels of disability and distress. In addition this group would still be at higher risk for developing psychosis but not explicitly labelled as thus. This could be viewed in the same way as diagnosing and treating angina not only because it is an illness in itself but also to prevent myocardial infarction (Arango, 2011). From our own research, we have seen that young people desire a label that validates/describes their psychotic like experiences. This term Attenuated Psychotic Syndrome offers this without the potential anxiety and connotations of being labelled 'at-risk', although it could be construed as reducing the diagnostic threshold for psychiatric illness.

The inclusion of a psychosis risk syndrome in the forthcoming Diagnostic and Statistical Manual may have indeed been too premature (Nelson and Yung, 2011) and the subsequent decision by the American Psychiatric Association working group to withdraw its inclusion can easily be justified. However its inclusion within the appendix for 'Criteria sets

and axes provided for further study' has been confirmed and seems worthwhile at this time (Carpenter and Tandon, 2013). We therefore hope that this decision will increase the scope for research that directly involves and listens to the views and concerns of those identified as this is an area of research that is clearly lacking and must be addressed immediately. It is unclear at this time whether this decision will reduce or increase attention and enthusiasm for the categorisation and recognition of future 'risk' in other areas of psychiatry such as bi-polar affective disorder (Manic depression; Bechdolf *et al.*, 2012).

Conclusion

In this paper we have outlined the current psychiatric practice of identifying individuals perceived to be at an elevated risk of developing a psychosis illness and the associated risks and benefits of this process. The issue of risk labelling has a broader relevance beyond psychiatry, though, as the widely accepted, though false, perception of mentally ill people is that they pose a high level of risk to others; indeed the risk they pose to society is often perceived to be much higher than it actually is, and the risks they pose to themselves much lower than in reality. Debates about risk in relation to mental health involve issues about individual rights and how they can be balanced with wider social needs for safety and the minimising of potential harms. However, as Heyman (2004) points out, it is impossible to predict with any accuracy who might harm or offend, leaving policy-makers and practitioners in a position of uncertainty. This position is usually dealt with by using the language of risk, and attempts to quantify levels of risk. Although the reported study is informative regarding the benefits of risk screening and psychiatric labelling, the findings are incongruent in comparison to those reported in other areas of health, possibly reflecting the studies exploratory nature. Finally it is unclear whether future risk identification in psychiatry and research focussing on the personal experiences of screening will be affected by the American

Psychiatric Association decision to omit the At-Risk Mental State as a full diagnostic term in the most recent adaptation of the Diagnostic and Statistical Manual.

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Table 1. Key demographic details

Participant	Age, years	Gender	Current symptom status at the time of interview
Andy	16	Male	Full symptom remission
Bethany	13	Female	ARMS
Claire	16	Female	ARMS
Donna	16	Female	ARMS
Ethan	15	Male	Full symptom remission
Frederick	18	Male	ARMS